LEO

YEAR 6

WE'RE BETTER TOGETHER!

LYMPHOMA EPIDEMIOLOGY OF OUTCOMES

WHAT'S INSIDE:

- ***PATIENT PERSPECTIVES AND HOW THEIR DIAGNOSIS CHANGED THEIR LIVES.***
- ***MAYO CLINIC HEMATOLOGIST DR. CARRIE THOMPSON, ON THE IMPORTANCE OF LONG-TERM STUDIES AND THEIR EFFECT ON LYMPHOMA SURVIVORSHIP.***
- ***FAQ & HOW TO CONTACT US***
- ***AND MORE!***

> **"WE ARE VERY GRATEFUL FOR ALL OF OUR COORDINATORS, INVESTIGATORS, RESEARCH STAFF, AND MOST IMPORTANTLY, THE LEO PARTICIPANTS FOR ALL THAT YOU CONTINUE TO DO TO MAKE LEO THE LARGEST AND MOST DETAILED STUDY OF LYMPHOMA SURVIVORS."**
>
> **James Cerhan, M.D., Ph.D. & Chris Flowers, MD**

2022

A PATIENT'S

PERSPECTIVE

The LEO organization consists of eight sites and universities across the United States and has consented just under 8000 patients to take part in the study. We asked several LEO study participants to share their story to give a patient's perspective of what it was like when they were first diagnosed with lymphoma.

Juan Davila
University of Miami, FL

Although I had heard of the word lymphoma as a cancer, I had no idea of what the condition entailed prior to my diagnosis. Because I was too shocked to learn that I had advanced Follicular Lymphoma (stage IV), I decided not to make any big decisions except to do as my oncologist, Dr. Lossos, told me. Through research, my sisters and I found that Dr. Lossos at Sylvester Comprehensive Cancer Center at the University of Miami was an eminent authority on lymphoma. However, there was a 6-month waitlist for an appointment with him. Thanks to a dear neighbor who worked at Sylvester, we got an appointment sooner. When I met Dr. Lossos, I knew he was the right choice.

After I was diagnosed, I was open about discussing my diagnosis to my family and a couple of friends, except my 84-year-old mother. I thought it would worry her too much and being a mid-octogenarian, I did not want to worry about her health. I figured that after the 7 months of R-CHOP chemo, I would be in remission. Though I was cancer free for 5 months (a period in which I underwent Rituximab maintenance immunotherapy), the lymphoma came back. That's when Dr. Lossos prescribed a bone marrow transplant. At the point, I decided to tell my mother. My family and friends were my real 'immune system' during treatment.

Surviving cancer cleared my vision just like windshield wipers do in a storm. Could withstanding so much suffering from chemotherapies and horrible side effects be the price one pays to have a sharper sensory perception? My respect for all living things has increased –from plants to insects, to birds and even to the biggest animals. Today, my awareness level of the present moment has also sharpened. I am more present and listen more acutely, allowing me to sense the interconnectedness of everything surrounding me.

Post-transplant, economic insecurity became the biggest battle to overcome after cancer. Thanks to the love from my family, friends, and the psychiatric/psychological team at Sylvester, I began to trust in my resilience. Today, I am steadily rebuilding as I grow stronger each day. I am regaining financial freedom through a new vocation that I truly enjoyed, not one that only breeds stress. With the help of Sylvester's Cancer Support Services, I realized that fighting cancer had really made me stronger, gave me a new worth, and forced me to endure, giving me tools to rebuild anew regardless of what others think I can or can't do.

My motivation to join the LEO study was one, because Dr. Lossos was a part of it and two, my desire to help others afflicted with this difficult illness. I would be honored and pleased if sharing part of my experience ended up helping someone. In fact, I literally owe Dr. Lossos my life. Never have I met such a fascinating, smart, and caring doctor. As earlier stated, when meeting Dr. Lossos, intuitively I felt that he truly cared about my well-being and was going to do whatever it took to keep me alive.

A PATIENT'S PERSPECTIVE

Joe Kanevsky
University of Miami, FL

We had heard of lymphoma before, but when I was diagnosed with Large B cell lymphoma that particular type of cancer was something I was not aware of. It was discovered at the Veterans Administration in West Palm Beach, FL.

We found out I had lymphoma because I unfortunately needed to go to the emergency room for an unrelated health issue and perhaps by divine intervention, they gave me an ultrasound. And there it was…the big C! They told me that I needed to have a biopsy to figure out what the scan showed.

After I learned the results from the biopsy, my wife and I were shocked by the diagnosis. We decided that I would receive radiation, which involved driving up to the VA Monday thru Friday for a period of three weeks. In the meantime, my wife was researching every waking hour about large B-cell lymphoma. She learned that there was a great clinic in Miami called the Sylvester Comprehensive Cancer Center and we immediately made an appointment with a wonderful doctor, Dr. Jonathan Schatz. When we met with Dr. Schatz, he suggested a treatment called "mini chop" and I asked him whether I would be able to tolerate it. After several months of treatment it was time for my first PET scan to check the results. The treatment worked and I have been cancer free for three years.

I have been very open about my condition with family and friends. My wife did a lot of research and was completely supportive in my cancer journey. She was there for all of my treatments. I am grateful to the doctors and nurses who helped me get well. If my story and participation in the LEO study will help even a single person then it will bring joy to my wife and I. We hope it will help many people. It is so important not to be discouraged and to never ever give up!

Mr. Kanevsky's advice for newly diagnosed patients:

- Keep a positive attitude.
- Do your research.
- Prepare questions to ask your doctor.
- Be accepting of others' help.
- NEVER EVER GIVE UP!

"Before starting treatment, I had never been bald and even wore a long ponytail for many years.

Unfortunately, during my treatment, I lost my hair. Now, since finishing treatment, my hair has grown back and to my delight, I have three times as much and it is curly!"

A PATIENT'S PERSPECTIVE

Jonathan & Kallie Palmer
Emory University - Atlanta, GA

To read an interview from Kallie Palmer, Registered Nurse & wife of Jonathan Palmer, please visit:
https://leocohort.org/leo-patient-interviews/

My name is Jonathan Palmer, and I am currently in maintenance phase of treatment for Acute Lymphoblastic Leukemia (B-ALL). This "journey" started in 2019 when I was getting a routine physical with my general practitioner. In March and April of 2019, I began feeling tired, having difficulty walking upstairs, losing my appetite, having night sweats, and regularly running fevers. After pushing me for weeks to make an appointment with our general practitioner, my wife finally demanded I go to the doctor. When I arrived and began telling my doctor of all these symptoms, she decided to run some blood tests and asked if I could stay until the results were back. My doctor came back some time later and sat down. "Your blood counts are irregular and may be indicative of cancer," she said. "Unfortunately, I cannot let you go home today. I need you to go to the emergency room. I have already called ahead and have referred you to a specialist I know."

When I heard those words "may be cancer", I could not believe it. It was a shock. It literally had never crossed my mind that I could EVER get cancer. I did not smoke, I was relatively young, I exercised, and tried to eat healthy. It just did not make sense. On May 14th 2019, I walked into an outpatient facility as a concerned patient and left being diagnosed with B-ALL. From there my life took a sharp turn into a direction I was quite unfamiliar with.

I spent 22 days on the oncology floor of Emory Winship Cancer Institute in June of 2019. During that time, decisions had to be made about living as a cancer patient and trying to hold together your "old life." Bills do not stop, work is waiting, and a million other personal and financial decisions had to be made in "preparation" of something that was always in the back of my mind. When I was inpatient, the option to participate in the LEO study was brought up, and I decided to join. By participating, I could shape future treatment approaches and maybe help others.

Cancer has taken away one thing and yet given another. Cancer takes away TIME. Time that you might not have. It urged me to dig deep and make sense of it all. I finally learned to let go. I let go of the fear. What's the point of being afraid? Is cancer scary? A resounding YES, but the rest falls on you on how to handle it. I've learned that addressing the emotional and mental toll of cancer is just as important as treating the physical aspects. I urge anyone reading this to know that your mental health is important and to not shy away from asking for help. I found working with a psychiatrist or joining a support group was a great way to wade through the waters of cancer treatment. I've always lived by the motto, "you can't change the circumstance, but you can change how you react to it." I learned to live each day to the fullest and that the loss of time made it that much more precious.

"We want to sincerely thank our highlighted LEO participants for sharing their stories and for their continued participation on this study. We hope that by reading their stories, that other cancer patients will gain insight on how to move forward from their diagnosis."
- The LEO Correspondence Committee

LEO

SURVIVORSHIP

Carrie Thomson, M.D.
Associate Professor
College of Medicine
Mayo Clinic

What is survivorship?

According to the National Cancer Institute, *"survivorship focuses on the health and well-being of a person with cancer from the time of diagnosis until the end of life. This includes the physical, mental, emotional, social, and financial effects of cancer that begin at diagnosis and continue through treatment and beyond."*

This definition is useful in lymphoma care, as there are many different types of lymphoma, from chronic diseases where individuals are living with the disease to aggressive cancers that are put into remission after treatment. No matter what type of lymphoma you have, we know that the diagnosis, treatment, and follow-up can have short and long-term effects. We are interested in learning more about these events in your cancer care. Being part of the LEO cohort is really important, as it is one of the only long-term research projects studying lymphoma patients!

What Information we are collecting?

The information patients provide in their questionnaires helps our team gain a better understanding of lymphoma. This data also helps the LEO team find ways to improve patient care and quality of life for individuals diagnosed with lymphoma in the future. The questionnaires help us identify what is important to you and what we should study. For example, in the 3- and 5-year questionnaires we are gathering details about your:

- *Exercise/physical activity*
- *Smoking/drinking habits*
- *Activities of daily living*
- *Depression/anxiety*
- *Treatment side effects*
- *Current survivorship care plan*

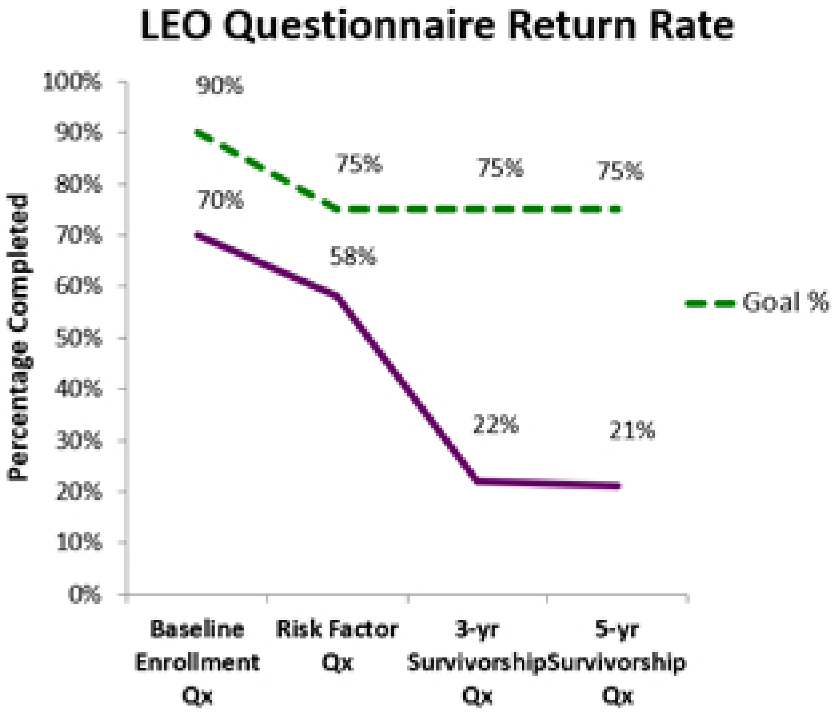
What have we learned so far?

Quality of Life Studies:

LEO Investigators studied the quality of life in survivors of aggressive lymphoma from the time of diagnosis out to nine years and found that quality of life was higher than that of the general US population.

Physical Activity Studies:

Other important studies looked at the role of physical activity in newly diagnosed lymphoma patients and 3-year survivors. Those with higher levels of physical activity had improved overall and lymphoma-specific survival, leading to the recommendation that all patients with lymphoma should follow exercise guidelines for cancer survivors (American Cancer Society recommends moderate-intensity aerobic exercise at least 3 times per week, for at least thirty minutes).

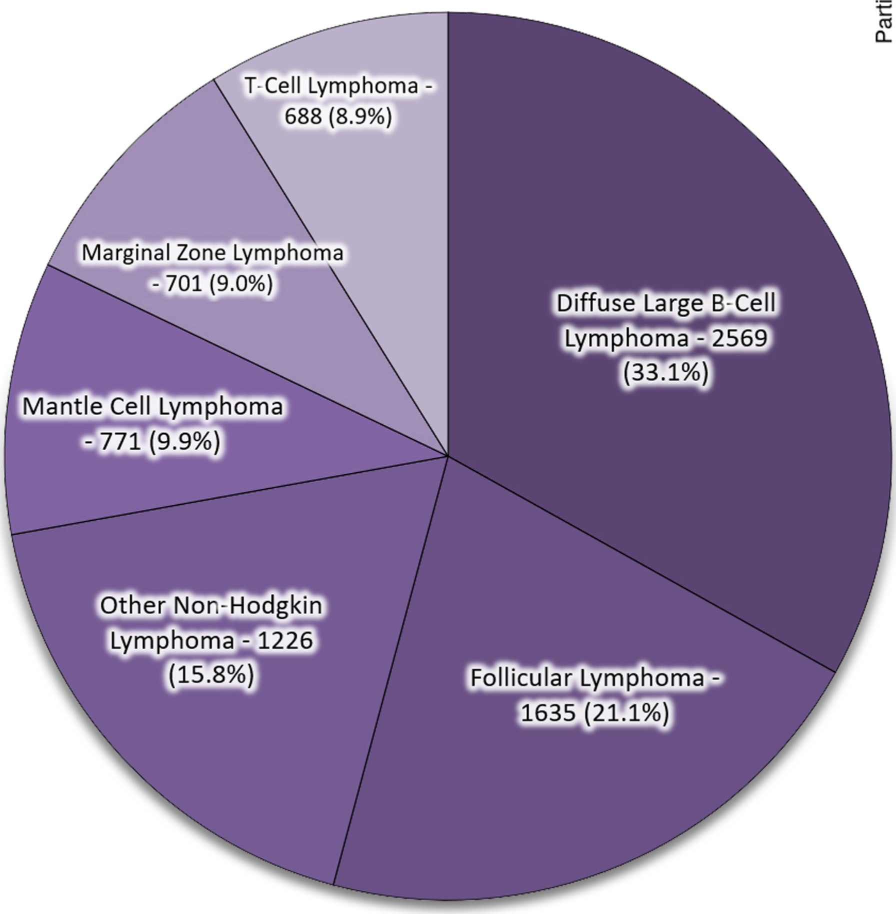


The research would not be possible without your participation. We need your help to reach our goals!

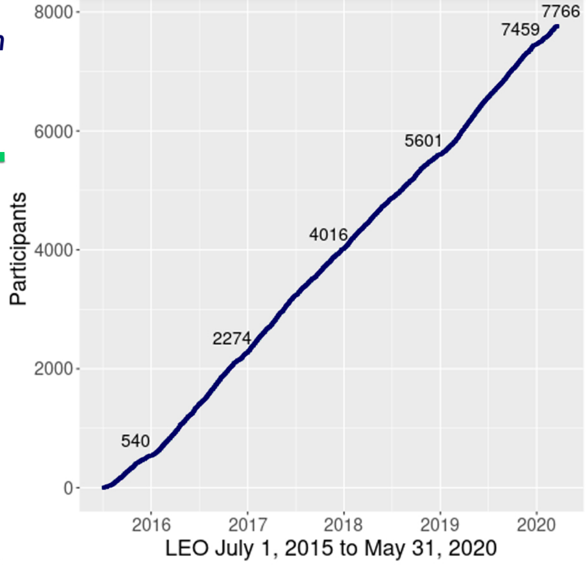
LEO STATISTICS

With the help of the LEO statistics team, we have compiled three graphs that show what the LEO study looks like behind the scenes. These graphs depict LEO study enrollment through the years, as well as age, sex, and subtypes of LEO study participants.

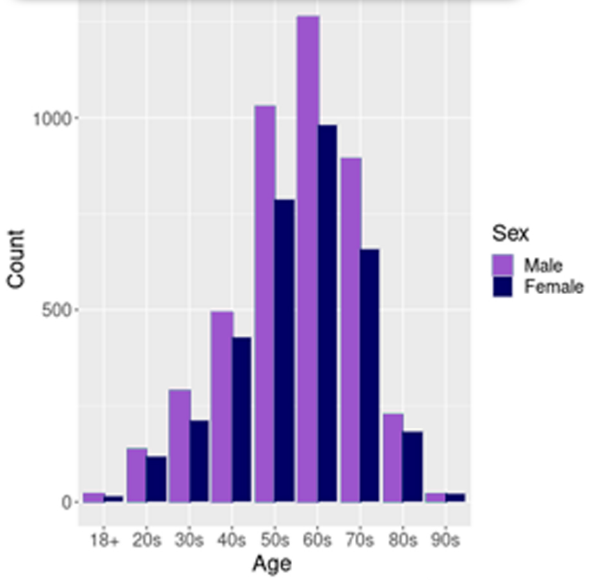
LEO Study Participant Subtypes



LEO Study Enrollment Over Time



Age & Sex of LEO Participants



FREQUENTLY ASKED QUESTIONS

“Why should I continue to fill out the questionnaires even after I’ve achieved remission?”

It is extremely important that we continue to receive surveys even after patients have been declared in remission. We try to follow patients over a lifetime and no evidence of disease is just as valuable information as those that have reported relapses or new treatments. The more data we can collect, the more questions we can answer. With more data points, we can detect important trends in outcomes for thedifferent sub-types of lymphomas.

“What if I’ve achieved remission but have other health problems that would affect my survey answers?”

The survey questions are meant to measure overall quality of life not just the impact of lymphoma. For example, if your overall pain has increased due to an old back injury that is unrelated to your cancer, please report that pain in your survey answers (this includes any physical, social, and emotional effects from the Covid-19 pandemic). We repeat similar questions each time you receive a survey. We do this on purpose to measure how financial burdens,treatment side effects, social relationships, and mental health affect overall survivorship over time.

LEO FROM HOME

While coordinators were working from home, they were learning how to remotely consent patients over the phone and via email. The LEO team created an automated electronic follow-up system to provide a more efficient, faster, and paperless process for patients to complete their questionnaires. As a general reminder, please continue to check your email/junk mail folder for links to your scheduled questionnaires. If you have recently updated your email address, please send a message to lymphoma@mayo.edu and we can update it in our database. Your continued participation in this research is so greatly appreciated as we continue to move forward with our research despite the hardships of the pandemic.

WEILL CORNELL MEDICAL COLLEGE

Peter Martin, MD
New York, NY

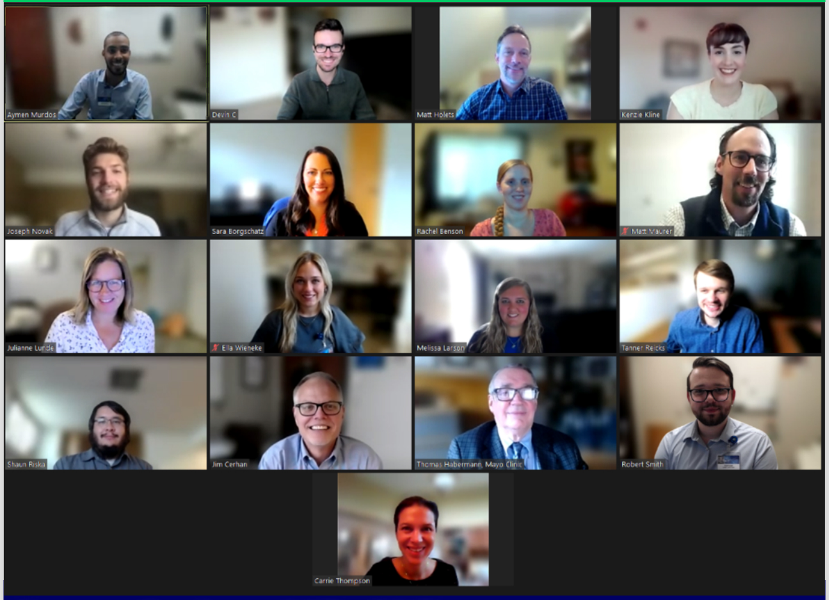
Phone: 646-962-9408
Email: arg2006@med.cornell.edu
Website: leocohort.org/weill-cornell/

EMORY UNIVERSITY

Jonathon Cohen, MD
Atlanta, GA

Email: bjcopel@emory.edu
Phone: 404-778-3942
Website: leo.winshipcancer.emory.edu

MAYO CLINIC



James Cerhan, MD, PhD
Rochester, MN

Email: lymphoma@mayo.edu
Phone: 1-800-610-7093
Website: leocohort.org/mayo-clinic/

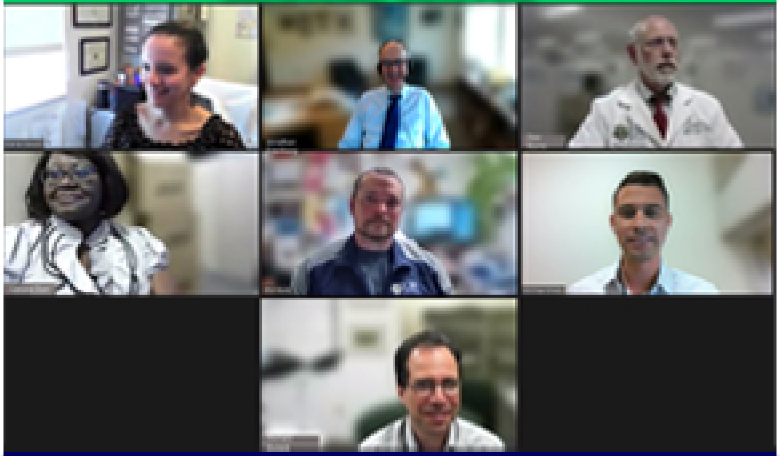
UNIVERSITY OF IOWA

Brian Link, MD **Iowa City, IA**
Email:
cancercenter-mer@healthcare.uiowa.edu
Phone: 319-353-6125
Website:
cancer.uiowa.edu/molecular-epidemiology-resources-core

All contact information can be found at: leocohort.org

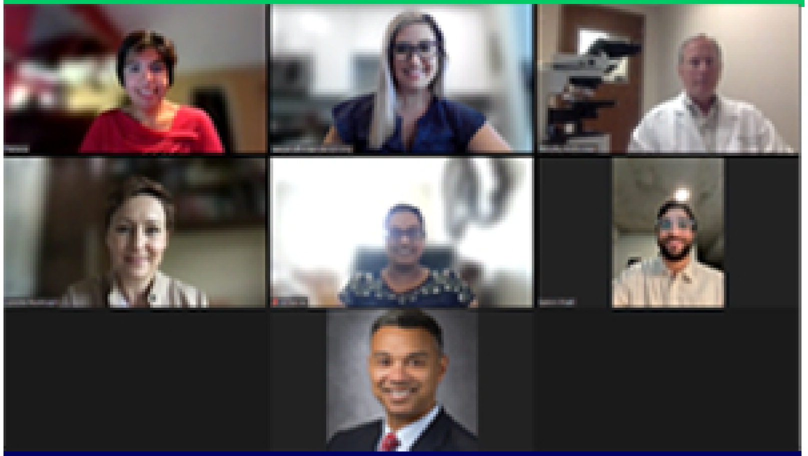
LEO FROM HOME

UNIVERSITY OF ROCHESTER MEDICAL CENTER



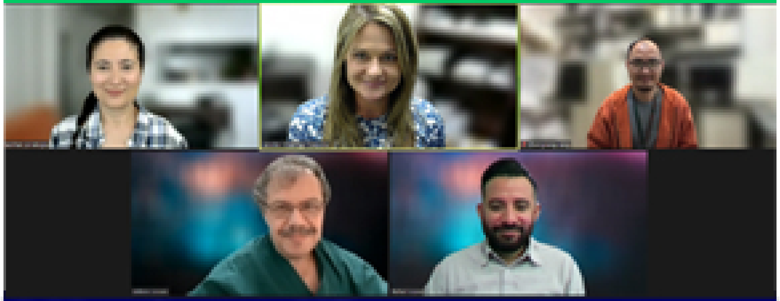
Jonathan Friedberg, MD
Rochester, NY
Phone: 585-273-3903
Email: don_burns@urmc.rochester.edu
Website: urmc.rochester.edu/cancer-institute.aspx

MD ANDERSON CANCER CENTER



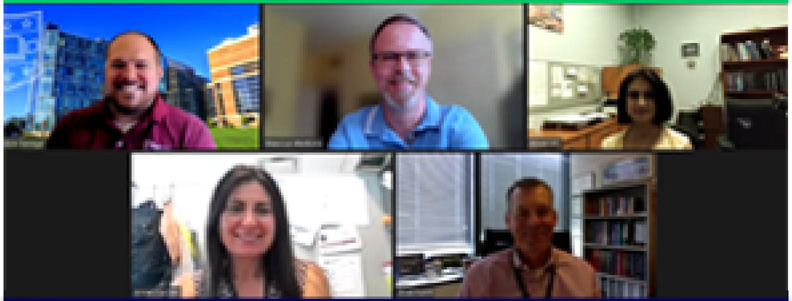
Chris Flowers, MD
Houston, TX
Phone: 713-792-0215
Email: ryzquier@mdanderson.org
Website: leocohort.org/md-anderson-cancer-center

UNIVERSITY OF MIAMI



Izidore Lossos, MD
Miami, FL
Phone: 305-243-2712
Email: nyorukoglu@miami.edu
Website: leocohort.org/university-of-miami

WASHINGTON UNIVERSITY



Brad Kahl, MD
St. Louis, MO
Phone: 314-273-2812
Email: dawnb@wustl.edu
Website: leocohort.org/washington-university

Useful Links

LEO Cohort:
LEOcohort.org

Lymphoma & Leukemia Society:
LLS.org

American Cancer Society:
cancer.org

LEO Lymphoma Epidemiology of Outcomes